



STATEWIDE CCO MEMBER & FAMILY ADVISORY COLLABORATION
Testimony to the Assembly Ways and Means and Senate Finance Committees
Joint Legislative Budget Hearing on Mental Hygiene
February 14, 2022

My name is Rachele Kivanoski and I am the parent of a 38 year old son with Autism and Intellectual Disability who has been receiving State funded services for over 30 years. I represent the Statewide CCO Member & Family Advisory Collaboration and our 110,000 members and their families. I want to thank Senator Kreuger and Assembly Member Weinstein and all the Committee members for the opportunity to share our views on the proposed budget for the Office of People with Developmental Disabilities (OPWDD).

We are enormously grateful for the new spirit of collaboration displayed by Governor Hochul and Acting Commissioner Neifeld. For the first time in far too long, we believe that this Administration not only sees people with Intellectual and Developmental Disabilities (IDD) and their families but has also proposed many significant measures to improve our lives. Even while navigating the devastating twin emergencies of a recurrent and stubborn pandemic and a workforce shortage of unprecedented magnitude, State leadership is striving for a more equitable and compassionate future. We are hopeful that the days of the State making investments into the OPWDD system by stripping away needed resources from within the system are finally over.

So many of the budget measures are potentially life changing for our population. The enhanced ISS subsidy now makes independent living in rental housing a realistic goal for those people with IDD who choose this option. We also applaud the monies allocated for the creation of new supported housing. However, these measures alone cannot close the gap between available and needed housing that has reached crisis proportions. We urge you to mandate a comprehensive residential needs survey to quantify what types of housing and staffing support are needed now and over the next ten years.

We are hopeful that the monies for enhancing employment opportunities for people with disabilities will create new momentum and a changed culture that will promote greater

inclusion of people with IDD in the workforce after decades of little progress. We are also extremely grateful for the provision of the first in a decade significant COLA for all providers after ten years of virtually no increase, which will help to financially stabilize IDD providers and will also enhance the resources available for people under Self Direction.

The sad reality is that none of these wonderful new programs are viable without a stable workforce. The magnitude of the DSP workforce emergency has been acknowledged by the Governor and our Acting Commissioner. This crisis, a result of a decade of fiscal starvation of our sector, was dramatically accelerated by the COVID pandemic. The minimal wage increases that were granted to our Direct Support Professionals (DSPs) in the last few years were effectively erased with the concurrent rise in the statewide minimum wage. Even prior to the pandemic, staff recruitment and retention became an increasing challenge in large part due to inadequate salaries and benefits.

Those DSPs who continued to work during the pandemic, like all the essential frontline workers, endured daunting workplace conditions with risk to themselves and their own families. They had to cope with new infection control work responsibilities for this medically vulnerable population, residents in lockdown, and growing behavioral management challenges as our members became more and more isolated with loss of stabilizing routines. There is also a vicious cycle of staff shortages fueling unrelenting mandatory overtime leading to staff burnout and more shortages.

This devastating lack of Direct Support Professionals means that many people with IDD have returned to a quasi-institutional lifestyle spending days and days indoors because there are no staff to help them go out into the community. For those fortunate enough to be called back to their Day Habilitation programs, the programs are largely confined to indoor activities. Many are unable to resume the volunteer job activities that developed vocational skills and instilled pride and purpose in their days. Supported Employment programs are restricted due to the shortage of Job Coaches. Virtual programming, while a lifeline for some during lockdowns, is no substitute to being out in the world, interacting with peers and working.

Some people with IDD who live on their own often spend entire days in their beds or wheelchairs with no DSP or home care staff available to help them. People utilizing Self Direction who are living in non-certified housing have often had to return to stay with their families due to shrinking availability of staff supports and do not have enough DSPs to support community habilitation activities.

The lack of supports for people living with their families have often stretched caregiver emotional and financial resources to the breaking point. Family members are unable to work because of the demands of caring for their loved ones, who now have no day habilitation program, respite program or Comm Hab worker due to the DSP staffing crisis.

Group homes are closing, consolidating, or struggling to provide anything beyond the most basic health and safety needs of the residents. OPWDD leadership informed us that many

grants that were previously provided to establish new certified residences were returned by providers because they are unable to recruit new staff. There are hundreds of individuals deemed to be in emergent or urgent need of a certified placement, but vacancies in existing homes remain unfilled due to lack of staff.

It is undoubtedly true that the impact of this crisis-driven lack of services most adversely affects our most vulnerable members. There is no opportunity to address pre-existing inequalities in access for many people from immigrant communities and communities of color when there are no DSPs to staff new initiatives. Similarly, people with more complex physical and behavioral needs are relegated to the bottom of the list when staffing is so precarious.

There are thousands of CCO members who have no involved family to help advocate for them and suffer most acutely from the isolation of the pandemic with lack of critical staff continuity and support. Our Care Managers strive to be their stable support system but are frustrated by their inability to find appropriate programming and staff supports essential to the members' quality of life.

The generous DSP bonuses provided through the Federal ARPA funds and supplemented in the Governor's budget will, at best, help to maintain this unacceptable status quo. One time funding does not raise the base pay for any DSP, beyond the money to bring Upstate DSP's up to the new prevailing minimum wage. Taking care of this vulnerable and extremely diverse and complex population is not a minimum wage job.

Career ladders, credentialing and enhanced education are all wonderful initiatives that will not advance recruitment if compensation remains at minimum wage levels. We are terrified that the workforce crisis will only deepen as the bonuses run out and people with IDD will face a return to more and more institutional style care and narrowing options for services despite the very best intentions of the Administration and providers.

We need a plan to bring the entire Direct Support Professional workforce to a living wage commensurate with their skills and responsibilities. We urge the Legislature to start the process of permanently increasing DSP wages in this budget by taking the following actions:

- Convert the last \$3000 bonus payments proposed in the FY23 budget to salary increases, approximately 10% now;
- We support the impetus behind OPWDD's proposed Article 7 regulation that would require providers to prioritize use of the COLA to increase salaries of the lower paid workers. We believe this should include other direct care workers such as Behavioral Intervention Specialists and Job Coaches. We request additional language that stipulates a specific percentage consistent with agencies' overall labor costs be part of this mandate.
- Make an additional investment of \$100 million in State funds, which would total \$200 million total investment with the Federal matching funds. This would permanently raise DSP wages by another 4%.

- The 3 actions above would permanently raise wages for all DSPs (provider based and in Self Direction) by nearly 20% but still below a living wage
- Appoint a Task Force to recommend the required steps to phase in a full regionally based living wage for DSPs within the next three years.

We believe that these measures may begin to stabilize our system in crisis and set the basis to truly reach the goals advanced by Governor Hochul and Acting Commissioner Neifeld to support fully integrated lives for people with Intellectual and Developmental Disabilities.